Seizure 21 (2012) 205–210

Contents lists available at SciVerse ScienceDirect

Seizure

journal homepage: www.elsevier.com/locate/yseiz

Factors influencing the costs of epilepsy in adults with an intellectual disability

Mark Pennington [a,*], Elizabeth Prince [b], Naomi Bateman [b], Joanne Gray [c], Tim J. Croudace [d], Marcus Redley [b], Nicholas Wood [e], Howard Ring [b]

[a] Department of Health Services Research & Policy, London School of Hygiene & Tropical Medicine, London, UK
[b] Cambridge Intellectual and Developmental Disabilities Research Group, University of Cambridge, Cambridge, UK
[c] School of Health and Social Care, Teesside University, Middlesbrough, UK
[d] Department of Psychiatry, University of Cambridge, Cambridge, UK
[e] NHS South Gloucestershire Learning Difficulties Service, Bristol, UK

ARTICLE INFO

Article history:
Received 20 May 2011
Received in revised form 31 October 2011
Accepted 22 December 2011

Keywords:
Epilepsy
Cost
Intellectual disability
Management

ABSTRACT

Purpose: Despite the common occurrence of intellectual disability (ID) in people with epilepsy, most studies of the cost of epilepsy have focussed primarily or exclusively on people without ID. This paper estimates the costs of supporting people with epilepsy and ID.
Methods: Prospective resource use and outcome data were collected on 91 participants from the east of England for seven months. Multivariate analysis was used to investigate the relationship between costs and patient and healthcare provider characteristics.
Results: Mean health care costs relating to epilepsy or ID were £2800 (3500 Euros, 5200 USD) p.a. Modelling suggests costs are lower for patients with more severe ID ($p = 0.014$); and higher for patients managed by a consultant neurologist ($p = 0.037$).
Discussion: Our findings support limited evidence from the literature of increased epilepsy costs in people with ID. Patterns of expenditure suggest clinical variation in the treatment of epilepsy according to the severity of ID, particularly in the absence of management by a consultant neurologist.

1. Introduction

Epilepsy imposes significant financial costs on individuals, families and the health care services supporting them. As a consequence, an understanding of the costs of epilepsy and the factors influencing those costs is important for the efficient delivery of care for people with epilepsy.[1] Whilst a number of studies have examined costs of epilepsy in regions around the world,[2–6] patients with significant intellectual disability (ID) (defined as an IQ of 70 or less) are often excluded. In addition, psychiatric co-morbidities, which occur at increased rates in those with ID[7] and social support costs for people with epilepsy and ID are rarely considered in detail.

Nevertheless, ID is relatively common in people with epilepsy, probably occurring in at least 25%.[8,9] Similarly, epilepsy is common in adults with ID,[10] with an overall prevalence of around 26%.[11] Epilepsy in adults with ID has a worse prognosis than epilepsy in the general population, with lower rates of seizure freedom,[9] high rates of multiple antiepileptic drug use,[12] and high rates of comorbidity[13] and mortality.[14] All these factors are likely to have important financial implications.

Hence adults with ID represent a distinct and sizeable proportion of those with epilepsy and one for which costs associated with delivery of epilepsy care remains under-researched. Our aim in this paper is to report the health and social care costs of supporting adults with active epilepsy and ID living in the community in the UK and to explore determinants of those costs.

2. Methods

2.1. Study design

This was a prospective study designed to collect data describing, over seven months, epilepsy; ID; quality of life; and health and social care utilisation for a group of adults with ID and epilepsy living in the east of England.

Entry into the study and collection of relevant background data took place during an initial recruitment visit. Participants then underwent four subsequent assessments at one, two, six and seven months. The study aimed to interview the same family member or paid carer on each occasion, as well as, where feasible, the participant. Assessments were carried out in participants' homes or at the site of day activities in which they were engaged.

* Corresponding author at: London School of Hygiene & Tropical Medicine, 15-17, Tavistock Place, London, WC1H 9SH, UK. Tel.: +44 020 7927 2780; fax: +44 020 7927 2701.
E-mail address: Mark.Pennington@lshtm.ac.uk (M. Pennington).

1059-1311/$ – see front matter © 2011 British Epilepsy Association. Published by Elsevier Ltd. All rights reserved.
doi:10.1016/j.seizure.2011.12.012

2.2. Participant recruitment

In the UK, epilepsy care for adults with ID is generally provided by some combination of hospital neurology or community ID health services and primary care. Community ID teams generally include nurses and psychiatrists with expertise in the management of epilepsy, and provide services to all adults with an IQ of 70 or less aged 18–65 years. The areas in our study were also within the catchment of teaching hospitals which included neurologists with a special interest in epilepsy and epilepsy specialist nurses. We sought to recruit 100 adults with ID and active epilepsy whose epilepsy was managed by a community ID team and 100 whose epilepsy was managed by a hospital neurology service. These numbers would have been sufficient to detect a difference of 3 points on the National Seizure Severity Scale with 96% power ($p = 0.05$), based on data from a pilot study in Cambridgeshire.

Eligible participants comprised all adults aged between 18 and 65 years with epilepsy and a record of at least one seizure, not considered to have been non-epileptic, in the six months preceding the study, with a full scale IQ below 71, living in Cambridgeshire or Norfolk and known to community ID and/or hospital neurology services in these counties.

Potentially eligible participants were initially identified by the clinicians providing their ongoing epilepsy management. All potential participants identified (334) were contacted. Of the 198 responses, 28 were ineligible. The remaining participants were included in the study provided consent was obtained from those able to give consent or, in the case of those lacking capacity to consent, assent was obtained from a carer under the provisions of the Mental Capacity Act (UK) (2005). The study was approved by the Cambridgeshire 2 Research Ethics Committee.

2.3. Assessments

At the initial recruitment visit the following information was collected; clinical details describing severity of ID, the nature of the epilepsy and its treatment, the prevalence of associated neurological and psychopathological comorbidities, accommodation and demographic information including ethnic origin.

At each of the four subsequent data gathering visits the following assessments were undertaken (unless frequency is otherwise specified); the abbreviated Glasgow Epilepsy Outcome Scale 35 (GEOS35)[15] (completed at first and fourth visits only); Epilepsy and Learning Disabilities Quality of Life Scale (ELDQOL);[16,17] seizure severity, measured using the seizure severity scale section of the ELDQOL; Glasgow Depression Scale for people with a Learning Disability (GDS-LD)[18] or the Carer Supplement to the scale (GDS-CS) for those unable to complete the GDS-LD themselves; EuroQoL (EQ-5D);[19] and a modified version of the Client Service Receipt Inventory (CSRI).[20] In addition, the primary carer completed a seizure diary for each participant covering the seven months of their involvement in the study. Members of the research team advised carers on how to complete the diary accurately using a protocol and reviewed it at each visit over the data collection period, with additional phone calls between visits to support reliable recording. Clinical details were gathered from carers and from examination of participants' clinical records by members of the research team.

The GEOS35 is a shortened version of the 90 item GEOS90 carer report.[15] Both measures have four subscales measuring carer "concerns about seizures", "medical treatment", "caring" and "social impact". The ELDQOL is a 70 item measure covering seizure severity, seizure related injury, antiepileptic drug (AED) side effects, behaviour, mood, physical, cognitive and social functioning, communication, overall health and quality of life and family concerns. The EQ-5D comprises two generic measures of health status: the 'tariff' is derived from assessment of functioning in mobility, self-care, social functioning, pain and mood; the Visual Analogue Scale (VAS) score is a simple scale of overall health from zero to 100 (best imaginable health).

The ELDQOL, EQ5D and GEOS35 instruments were scored according to published protocols. Missing data was imputed according to scoring protocols, provided sufficient questions had been completed. The EQ5D tariff scores were based on the UK general population values,[21] which generates scores from minus 0.594 to one (where one is equivalent to full health; zero represents death; and scores below zero represent health states rated worse than death).

2.4. Measurement of costs

The study took a societal perspective and attempted to capture all health and social care input relating to epilepsy and ID including primary care; inpatient and outpatient care; drug prescriptions; home adaptations; and support groups and activities for people with ID. This included valuation of the contribution of family carers. We modified the CSRI to make it relevant to people with epilepsy and ID and to record service use for the previous month only. The main modifications were undertaken to collect detailed data on social care provision, medications and activities relevant to people with an ID. (The modified questionnaire is available at http://www.ciddrg.org.uk/ldrome/.) The questionnaire recorded the location of activities and contacts with professionals and the mode of transport for participants where appropriate. Approximate contact times were recorded. Contact times were combined with appropriate unit costs (visiting or at place of work) for professionals and travel costs were added. Unit costs were taken predominantly from the Unit Costs of Health and Social Care[22] and all costs are in 2008 UK pounds sterling. Outpatient visits were split into three categories; ID psychiatry, neurology and other. Inpatient visits were categorised as ID psychiatry, neurology, specialty-specific or general medical (long stay) and a cost was assigned per day. Drug costs were calculated from detailed data on brand, dose and frequency combined with appropriate costs from the British National Formulary.[23]

Valuing time spent by carers is contentious.[24,25] We applied a unit cost equivalent to the average gross hourly wage by category of employment for hours spent caring by working carers as recommended by Gold et al.[26] We applied a value of £7 per hour for non-working carers, based on the mean unskilled gross wage rate. To avoid overestimating care costs we classified caring duties into four categories: hours directly giving care; hours of leisure activity; hours supervising; available but sleeping. Hours in each of the categories were weighted 1, 0.5, 0.2 and 0.1 respectively. The weights were chosen to reflect the likely burden of different caring activities.

Private sector care providers were reluctant to reveal accommodation and placement costs, hence we categorised participants' placements as residential care; supported living for people with ID; group homes; or village communities and applied appropriate unit costs.[22]

Few cost studies in the literature have utilised a control to ascertain costs attributable to epilepsy.[27] Most include all costs falling into categories whose most likely cause is epilepsy,[3,28,29] and this was the approach we used for health care costs. Costs for social care were assumed to be entirely attributable to the combination of ID and epilepsy. Cost data were divided into five broad categories to facilitate comparison with other studies: accommodation costs; social activities; primary health and community support (including aids and adaptations in the home); drug costs (relating to epilepsy or ID); and secondary health care (relating to epilepsy or ID). Primary health and social support